



THE SECRETARY OF HEALTH AND HUMAN SERVICES  
WASHINGTON, D. C. 20201

## **CHARTER**

### **CHRONIC FATIGUE SYNDROME ADVISORY COMMITTEE**

#### **AUTHORITY**

The Chronic Fatigue Syndrome Advisory Committee (CFSAC) is authorized under 42 U.S.C. 217a, Section 222 of the Public Health Service Act, as amended. The Committee is governed by the provisions of the Federal Advisory Committee Act, as amended (5 U.S.C., App.), which sets forth standards for the formation and use of advisory committees.

#### **OBJECTIVES AND SCOPE OF ACTIVITIES**

The purpose of the CFSAC is to provide advice and recommendations to the Secretary of Health and Human Services (HHS), through the Assistant Secretary for Health (ASH), on issues related to myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS).

#### **DESCRIPTION OF DUTIES**

The Committee shall advise and make recommendations to the Secretary, through the ASH, on a range of topics including: (1) opportunities to improve knowledge and research about the epidemiology, etiologies, biomarkers and risk factors for ME/CFS; (2) research on the diagnosis, treatment, and management of ME/CFS and potential impact of treatment options; (3) strategies to inform the public, health care professionals, and the biomedical academic and research communities about ME/CFS advances; (4) partnerships to improve the quality of life of ME/CFS patients; and (5) strategies to insure that input from ME/CFS patients and caregivers is incorporated into HHS policy and research.

## **AGENCY OR OFFICIAL TO WHOM THE COMMITTEE REPORTS**

The Committee shall provide advice and make recommendations to the Secretary, through the ASH. The ASH shall be given the responsibility to coordinate and monitor the implementation of those recommendations adopted by the Secretary.

## **SUPPORT**

Management and support services for Committee activities shall be provided by staff from within the Office of the Assistant Secretary for Health, which is organizationally located in HHS. The ASH shall provide direction and guidance for services performed to support CFSAC activities and operation.

## **ESTIMATED ANNUAL OPERATING COST AND STAFF YEARS**

The estimated annual cost for operating the Committee, including the approved stipend and reimbursement of travel expenses for the members, but excluding staff support is \$40,675.00. The estimate of annual person-years of staff support required is 1.0, at an estimated annual cost of \$155,517.00.

## **DESIGNATED FEDERAL OFFICER (DFO)**

The Designated Federal Officer (DFO) for the Committee will be selected by the ASH from among full-time or permanent part-time staff within OASH. In the event that the DFO cannot fulfill the assigned responsibilities for the Committee, then the ASH will temporarily select one or more full-time or permanent part-time program staff to carry out the assigned duties.

The DFO will assure coordination and communication between CFSAC and the HHS agencies. In coordination with the Committee Chair, the DFO will act as liaison for the Committee to HHS and various entities, i.e., other government agencies at the Federal, State, and local levels; the ME/CFS biomedical, academic, and research communities; the public; and other non- governmental organizations.

The DFO will schedule and approve all meetings of the Committee and any respective subcommittees that are to be held. The DFO will prepare and approve all meeting agendas; development of the meeting agenda can be done in collaboration with the Committee Chair and, when it is deemed to be appropriate, chairs of the workgroups. The DFO or designee will attend all meetings of the Committee and any respective subcommittees. The DFO also has authority to adjourn meetings, when it is determined to be in the public interest, and can be directed by the Secretary or designee to chair meetings of the Committee.

### **ESTIMATED NUMBER AND FREQUENCY OF MEETINGS**

The Committee will meet not less than two times a year. Meetings will be open to the public, except as determined otherwise by the Secretary or other official to whom authority has been delegated, in keeping with the guidelines under Government in the Sunshine Act, 5 U.S.C. 552b(c). The public will be given notification about all meetings that are scheduled to be held. Meetings will be conducted and records of the proceedings will be kept, as required by applicable laws and departmental policies. A quorum of the membership is required for the Committee to meet to conduct business.

When it is determined by the Secretary, or other official to whom authority has been delegated, that a meeting will be closed or partially closed to the public, in accordance with stipulations of Government in the Sunshine Act, 5 U.S.C. 552b(c) then a report will be prepared that includes, at a minimum, a list of the members and their business addresses, the Committee's functions, date and place of the meeting, and a summary of the Committee's activities and recommendations made during the fiscal year. A copy of the report will be provided to the Department Committee Management Officer.

### **DURATION**

Continuing

### **TERMINATION**

Unless renewed by appropriate action, the CFSAC will terminate two years from the date this charter is filed.

## **MEMBERSHIP AND DESIGNATION**

The Committee shall consist of thirteen members, including the Chair, who are appointed by the Secretary or the Secretary's designee. Of the thirteen members, seven shall be biomedical research scientists with demonstrated expertise in biomedical research applicable to ME/CFS; three shall be individuals with expertise in health care delivery, private health care services or insurers, or voluntary organizations concerned with the problems of individuals with ME/CFS, and at least three shall be patients or caregivers affected by ME/CFS. All voting members of this Committee are classified as special government employees (SGEs) and are subject to government ethics rules.

Committee members shall be appointed to serve overlapping terms of up to four years. Terms of more than two years are contingent upon renewal of the Committee charter by appropriate action prior to termination of the Committee charter. A member may serve up to 180 days after the expiration of the member's term if a successor has not taken office.

Non-voting *ex-officio* members may inform discussions of the Committee as CFSAC develops recommendations to be given to the Secretary. The Committee shall include eight non-voting *ex officio* members. The *ex-officio* membership will comprise representation from the Agency for Healthcare Research and Quality, Centers for Disease Control and Prevention, Food and Drug Administration, Health Resources and Services Administration, National Institutes of Health, Social Security Administration, U.S. Department of Veteran Affairs and the Department of Defense.

There will be three non-voting liaison representative positions. These positions will be occupied by representatives from organizations that are concerned with ME/CFS. The representative organizations will be selected by the DFO or designee and will serve two-year terms.

The voting public members will be paid at a rate not to exceed \$200 per day, plus per diem and travel expenses, as authorized by Section 5703, Title 5 U.S.C., as amended, for persons employed intermittently in the government service. The non-voting liaison representatives will serve without compensation, and will not receive per diem or reimbursement for travel expenses. Members who are officers or employees of the United States Government shall not receive compensation for their service on the Committee.

## **SUBCOMMITTEE**

As necessary, the Committee may establish *ad hoc* subcommittees composed of members of the parent Committee, convene conferences and workshops, and seek advice from non-member special consultants, with the approval of the Secretary or designee.

The established subcommittees shall provide advice and/or make recommendations to the parent Committee. A subcommittee may not report its findings directly to any federal official unless there is specific statutory authority for such reporting.

The HHS Committee Management Officer shall be notified upon establishment of each subcommittee and shall be provided with information on its name, membership, function, and estimated frequency of meetings.

## **RECORD KEEPING**

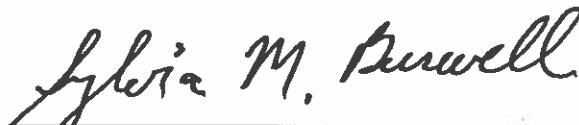
Records of the Committee and any established subcommittee will be handled in accordance with General Records Schedule 6.2, Federal Advisory Committee Records or other approved agency records disposition schedule. Applicable records will be made available to the public for inspection and copying, subject to the Freedom of Information Act, 5 U.S.C. 552.

**FILING DATE: September 5, 2016**

**APPROVED:**

SEP 05 2016

Date

  
Sylvia M. Burwell